

## Research Article

# Development of the Parent Forum: An in-person approach to supporting caregivers of youth with spinal cord injury

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**Context/Objective:** Describe development, implementation, review, and redesign of a hospital-based, in-person psychoeducational intervention for caregivers of youth with spinal cord injury (SCI) ages 7–17.

**Design:** Process evaluation/case study to describe intervention development, as well as preliminary evaluation data.

**Setting:** Pediatric specialty hospital.

**Participants:** 41 caregivers of youth with SCI.

**Interventions:** Caregivers attended an in-person intervention (“Parent Forum”), after which they were randomized into two groups: one received monthly phone calls from a mental health professional and the other services as usual. Caregivers were invited to attend a second Parent Forum one year later. The current paper focuses solely on the Parent Forum components.

**Outcome Measures:** Caregiver problem solving, study-specific satisfaction questions, and qualitative focus groups.

**Results:** After consulting with multiple stakeholders (including caregivers, clinicians, and researchers), the first Parent Forum was designed to focus on caregiver health/well-being. While caregivers from Parent Forum I reported greater positive problem solving and relatively high satisfaction scores, they also reported wanting more time together and more discussion of their children’s health. We redesigned Parent Forum II to incorporate this feedback which yielded positive results, particularly during focus groups.

**Conclusion:** The purpose of this manuscript was to share our development process to inform other teams engaged in intervention design for this or similar populations. Our experience emphasized the need to not only involve multiple stakeholders, but to pilot test intervention components, and be open to modifying them after receiving participant feedback. The final intervention model yielded positive reactions, but also emphasized the need for ongoing caregiver support.

**Keywords:** Spinal cord injury, Child, Caregivers, Problem solving

Spinal cord injury (SCI) is a life-altering disability with profound physical, psychological, and social effects. Individuals with SCI often experience paralysis, sensory loss, pain, and autonomic complications like bowel and bladder dysfunction, and ongoing health largely depends upon how well these chronic conditions are handled day-to-day.<sup>1</sup> Those who acquire SCI during childhood face increased challenges, as they must adjust

to their injury while navigating typical developmental stages.<sup>2</sup> However, pediatric SCI affects not only the child, but also parents and/or other familial caregivers. Caregivers of youth with SCI assume new care responsibilities that require additional time, skills, and resources, while often parenting other children, working outside of the home, and processing their own feelings over their child having sustained such a life-altering injury.

Caregiving takes a toll. Research has shown that caregivers of individuals with disabilities can experience significant psychological distress and burden, and low quality of life (QOL).<sup>3–10</sup> These challenges not only

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impact caregiver well-being but also the well-being of those for whom they care, particularly among youth with disabilities,<sup>11–17</sup> including SCI.<sup>18–20</sup> The psychosocial health of parental caregivers can impact how their children approach and engage in their lifelong journey of rehabilitation and reintegration; therefore, caregiver well-being is a vital piece of pediatric SCI rehabilitation. Despite this, to date, no research exists detailing intervention efforts with caregivers from this population.

The current manuscript is a process evaluation of the development of an in-person intervention for caregivers of youth with SCI. While outcome evaluations describe the effects of programs/interventions, process evaluations detail the development and implementation. Although outcome evaluations are important, alone they provide little information about *how* program or intervention effects occurred. While comprehensive intervention outcomes will be presented elsewhere,<sup>21</sup> we begin here by describing efforts to conceptualize, develop, implement and evaluate an in-person educational and support intervention for caregivers of youth with SCI. We aim to shed light on the work needed to develop new interventions and help others anticipate resources, challenges, and strategies for novel program development and implementation. Finally, like children without SCI, children with SCI are usually cared for by their parents. However, we use the term “caregiver” instead of “parent” throughout this manuscript to account for the variety of informal

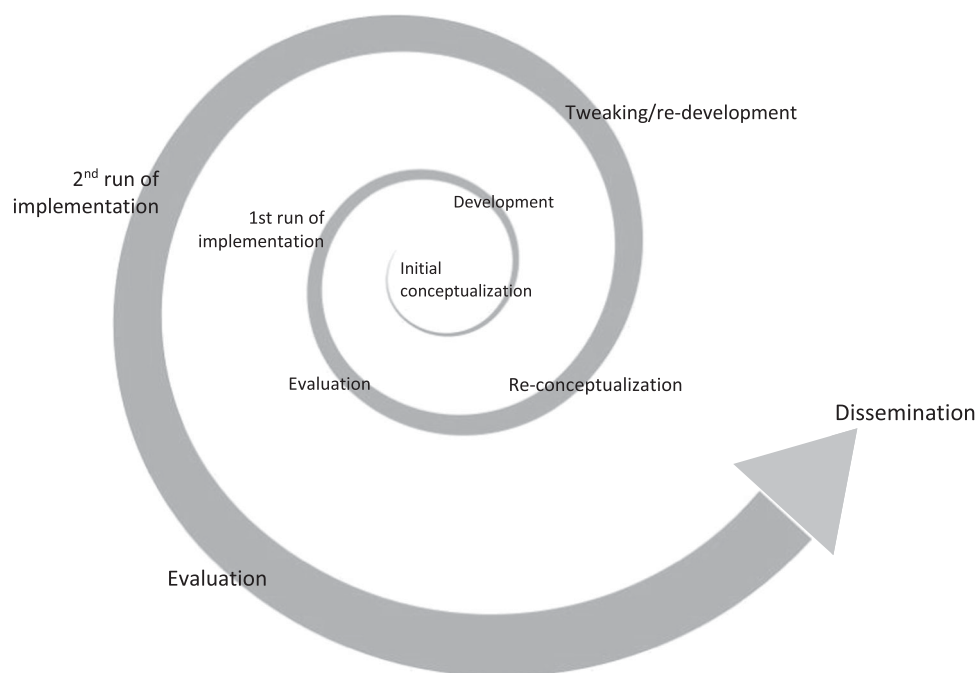
caregiving situations youth experience, as some are being raised by extended family members or other caregivers.

## Methods

A retrospective process evaluation case study<sup>22–24</sup> was conducted to explore the development, implementation and evaluation of an in-person caregiver intervention. An action research framework<sup>25–28</sup> (see Fig. 1) was used to focus this study on two cycles of program development/implementation: Cycle 1: initial conceptualization, development, implementation and evaluation, and Cycle 2: re-conceptualization, re-development/modification, re-implementation and supplementary evaluation work. Program archives, including grant narratives, reports, presentations, communication records and process notes, were used when available, and a retrospective collaborative inquiry process was used to flesh out details not explicit in program archives. Throughout this process, research team members revisited different stages and cycles of program conceptualization, development, implementation and evaluation.

## Context

Intervention development and process evaluation occurred at a pediatric specialty hospital in a large Midwestern city. This hospital is part of a larger pediatric healthcare network and offers comprehensive, interdisciplinary inpatient- and outpatient-services to



**Figure 1** Action Research Framework.

children and families living with pediatric orthopedic conditions. The hospital also fosters a strong investment in research and intervention development to improve clinical practice. As part of this effort, a two-year grant (April 2014-March 2016) was awarded by the Craig H. Nelson Foundation to develop and implement a pilot intervention for caregivers of youth with SCI. The proposal included an initial year-one, weekend-long “Parent Forum” for all caregiver participants in the study, random assignment of half of the caregivers to an experimental condition involving a year of monthly support calls with a mental health professional, and a follow-up year-two Parent Forum similar to the first. This manuscript will detail the development, implementation, evaluation and advancement of the in-person Parent Forum components only. In order to present the process evaluation findings in sequence with the development/evolution of this component of the intervention, measurement tools used to evaluate the Parent Forum are described in the Results section below.

### *Participants*

Caregivers of youth with SCI who were 7–17 years of age and had been injured for at least one year were recruited from both the pediatric healthcare network and other community organizations serving youth and families with disabilities. A total of 250 families were contacted about the study via mail or phone, 53 were consented, and 41 attended Parent Forum I, establishing them as study participants. One caregiver withdrew from the study within the first year due to personal reasons; the remaining 40 caregivers were invited to Parent Forum II, of which 26 attended. Participants of Forum II did not differ significantly from Forum I attendees on the majority of demographic variables; however, mothers and caregivers whose child received care at the host facility were more likely to attend Parent Forum II (Table 1). Reasons cited for not attending Parent Forum II included scheduling conflicts, travel issues, and personal/family health concerns.

## **Results**

### *Cycle one*

#### **Conceptualization**

The initial conceptualization of the Parent Forum was based on a literature review as well as caregiver feedback. Specific to the literature review, while little has been done among caregivers of youth with SCI, intervention efforts among caregivers of youth and adults with other disabilities and chronic illnesses offered important information regarding the critical ingredients of successful interventions. In general, existing literature suggested providing

a combination of intervention methods, particularly education, support, and skill-building, is most impactful.<sup>29,30</sup> A meta-analysis looking at intervention effectiveness among caregivers of adults with various disabilities found effects were largest for interventions that increased both caregiver skills and knowledge.<sup>31</sup> Another review of caregiver interventions concluded that, while education was the most frequently-used strategy, psychosocial interventions were generally more effective in terms of improving psychological well-being.<sup>32</sup>

Problem-solving interventions have demonstrated particular promise, including among caregivers of youth with chronic pain<sup>33</sup> and mental health problems,<sup>34</sup> and caregivers of adults with cancer<sup>35</sup> and SCI.<sup>36,37</sup> Kurylo, Elliott, and Shewchuk<sup>38</sup> developed a problem-solving training program called “FOCUS” (Facts, Optimism, Cope, Understanding, Solve) to support caregivers of adults who acquired a sudden and severe disability.<sup>39</sup> This program aims to help caregivers prioritize the multitude of issues they face, and involves a) identifying and clearly stating the highest-priority problem(s) and breaking it into manageable parts, b) helping individuals develop a sense of optimism regarding their problem-solving abilities, c) generating multiple solutions to the problem, d) outlining how to make an informed and appropriate solution choice, and e) implementing a solution and then reviewing the outcome to evaluate how the solution worked.<sup>38,39</sup> An evaluation of this problem-solving training among caregivers of adults with SCI found that the intervention group experienced a significant decrease in dysfunctional problem solving.<sup>36</sup>

Taken together, this literature yielded critical information regarding intervention development for caregivers of youth with SCI, including the importance of providing multiple intervention mechanisms, including education, skill-building, and social support; and involving problem-solving training as a key component. In addition to reviewing the literature, our team also gathered data directly from caregivers of youth with SCI about their intervention needs as part of a larger study examining relationships between psychosocial outcomes of youth with SCI and their caregivers.<sup>19,40–44</sup> Most relevant to the current study, we systematically asked caregivers how we as a hospital could support them as they cared for their children. The most frequently-cited response was the desire to connect with other caregivers. One parent specifically suggested hosting a “forum of parents” to connect with others but also to learn more about skills including effective problem solving. These themes were echoed during informal conversations with caregivers about what supports might be helpful as they cared for their children. Caregiver requests for

**Table 1** Demographics of Parent Forum (PF) participants and between group significance tests.

	Mean (SD), Range or % (Frequency)			Between Groups Tests of Significance <sup>1</sup>
	Caregivers Participating in PF I (n = 41)	Caregivers Participating in PF II (n = 26)	Caregivers Participating in PF I only (n = 15)	
CG Average Age	41.2 (SD = 7.9)	40.3 (SD = 7.7)	42.7 (SD = 8.1)	ns
CG Role (Mother)	85.4% (35)	96.2% (25)	66.7% (10)	Fisher's Exact Test = .018
CG Marriage status (Married)	61.0% (25)	65.4% (17)	53.3% (8)	ns
CG Race (White)	85.4% (35)	88.5% (23)	80.0% (12)	ns
CG Highest Education (At least some college)	85.4% (35)	84.6% (22)	86.7% (13)	ns
Child Current Average Age	11.49 (SD = 3.2)	11.3 (SD = 3.4)	11.9 (SD = 2.7)	ns
Child Average Age of Injury	4.3 (SD = 4.1)	4.2 (SD = 4.4)	4.6 (SD = 3.7)	ns
Child Average Injury Duration	6.9 (SD = 3.9)	6.8 (SD = 3.9)	7.1 (SD = 4.0)	ns
Child Sex (Male)	63.4% (26)	57.7% (15)	73.3% (11)	ns
Child Race (White)	80.5% (33)	80.8% (21)	80.0% (12)	ns
Child Severity of Injury (AIS A)	71.4% (25)	68.2% (15)	76.9% (10)	ns
Child Level of Injury (Paraplegia)	73.2% (30)	76.9% (20)	66.7% (10)	ns
Child Injury Etiology (Vehicular-related)	46.3% (19)	50.0% (13)	40.0% (6)	ns
Hospital Affiliation (Study Host)	56.1% (23)	69.2% (18)	33.3% (5)	$\chi^2 (1) = 4.98, p < .05$

<sup>1</sup>Chi square and Fischer's Exact Test were used for dichotomous variables and Independent Samples Mann Whitney U Test was used for continuous variables.

education, problem-solving training, and peer-support mirrored many of the successful research intervention studies described above, so became the basis of our pilot intervention efforts.

### Development of Parent Forum I

In order to develop an intervention that would be grounded in both research and consumer perspectives, the core research team (which included the first, second, and fourth authors) convened two groups. The first was a *Curriculum Committee*, composed of 13 clinical providers of youth with SCI and their families from the disciplines of pediatric medicine, nursing, psychology, social work, clinical dietetics, and recreational, physical, and occupational therapy. This group helped revise an initial draft of the agenda for the Parent Forum I curriculum that had been developed by the core research team, brainstorm several ideas regarding session speakers and logistics, and refine curricular offerings. Several members of the *Curriculum Committee* went on to serve as presenters for various sessions during the Parent Forum weekend, as they were considered experts in their respective specialties.

The second group, an *Advisory Board*, included seven researchers with expertise in the areas of caregiver

interventions, problem solving, and families of youth with disabilities and SCI in particular. This group advised on the curricular content and logistics for the forums and on the design and evaluation of the intervention, including measurement tools and participant retention. Two caregivers of young adults with pediatric SCI recruited for the *Advisory Board* also provided extensive feedback on the design of the Parent Forum through phone conversations and emails.

Of note, across the two groups, we received some contradictory feedback regarding how best to use unstructured time, as some thought this time would be ideal for caregivers to connect, while others were concerned that free time would cause quieter caregivers to feel uncomfortable, and still others cautioned that unstructured time could allow more negatively vocal caregivers to set a destructive tone. Balancing this caution with the caregivers' previously articulated desire to connect was something we tried to rectify throughout the two iterations of the Parent Forum.

### Implementation of Parent Forum I

The Parent Forum I was a weekend-long program, where caregivers chose one of two weekends in August 2014 to attend, to accommodate their schedules. The

**Table 2** Parent Forum I Agenda.

DAY 1: 12:00–6:15pm Time	Activity	Staff
12:00–12:30pm	Lunch	
12:30–1pm	Intro/Purpose: Overview of the Forum Logistics for the weekend	Project Investigator (PI) Study Coordinator
1:00–1:30pm	Get-to-know-you activity	Recreation Therapist
1:30–2:20pm	Problem-solving: Introduction to FOCUS problem-solving training	Professional Counselor
2:20–2:40pm	Break	
2:40–3:10pm	Maintaining your physical health (diet)	Dietician
3:10–3:30pm	Maintaining your physical health (exercise)	Physical Therapist
3:30–3:40pm	Lifting/ergonomics activity	
3:40–4:20pm	Maintaining your emotional health	Clinical Psychologist
4:20–4:40pm	Meditation activity	
4:40–4:50pm	Break	
4:50–5:30pm	Identifying and cultivating sources of emotional support	Social Worker/Former Director of Spinal Cord Injury Services
5:30–6:15pm	Dinner	
DAY 2: 9am–3pm		
9:00–9:30am	Breakfast with smoothie station and education	Dietician
9:30–10:45am	Problem-solving: Completion of FOCUS problem-solving training	Professional Counselor
10:45–10:55am	Movement to music activity	Dietician
10:55–11:10am	Break	
11:10–11:50am	Age- appropriate developmental achievements	Nurse + Nurse Practitioner
12:00–1pm	Lunch	Pediatrician
	Evaluating sources of information and various treatment options	
1:00–2:15pm	Advocacy training	Social Worker + Advocacy Professional
2:15–3pm	Wrap up/questions/next steps	PI + Study Coordinator

agenda was identical for both weekends, and involved two half-day sessions providing educational, skill-building training, and psychological support to caregivers in an in-person, group format (see Table 2 for agenda). The grant funded travel, meals, and accommodations, and project staff coordinated all travel with assistance from a travel agency. Caregivers were given their preference for travel means (i.e. train, car, plane) and were allowed to bring their child with SCI if not bringing them would prevent the caregiver from attending. One of the hospital recreational therapists was employed to develop activities for attending youth during the sessions.

The two half-day sessions provided caregivers with the option of arriving Friday night or Saturday morning, and then leaving Sunday night or Monday morning. Saturday's topics included an opening get-to-know-you activity; an introductory session on problem solving; sessions on maintaining caregiver physical and emotional health, and identifying and cultivating sources of emotional support; a stretching-and-lifting demonstration; and a meditation activity. Sunday's topics included a second session on problem solving; a movement activity; and sessions on age-appropriate developmental achievements, evaluating sources of information and various pediatric treatment options, and advocacy. Sessions were 30–45 min long, and were facilitated by members of the *Curriculum Committee* and/or the core research team using Microsoft PowerPoint. Presentations and additional information were provided to all study participants on a flash drive to take home for reference and to share with others (e.g. partners and/or fellow caregivers). All intervention activities occurred at the hospital.

In addition to the structured activities mentioned above, the weekend also allowed for unstructured time and opportunities for caregivers to connect with each other. Project staff reserved rooms for caregivers at a nearby wheelchair-accessible hotel in a safe, well-populated area that offered luxury accommodations, onsite dining, and an abundance of entertainment within walking distance. Project staff facilitated all travel between the hotel and hospital. This travel time offered additional opportunities for caregivers to build relationships outside of structured activities, as did meal times, including Saturday lunch/dinner and Sunday breakfast/lunch.

### Evaluation of Parent Forum I

To evaluate caregiver skill development, we collected problem-solving data two weeks before and immediately after Parent Forum I using the *Social Problem Solving*

*Inventory, Revised, Short Form (SPSI-R:S)*. The SPSI-R:S is a self-report measure of problem-solving styles and solution generation,<sup>45</sup> consisting of 25 items with five component scales. Two scales measure problem-solving orientation (Positive: approaching problems as challenges,  $\alpha = 0.795$ ; and Negative: approaching problems as threats,  $\alpha = 0.837$ ) and three scales measure problem-solving style (Rational: applying sensible and systematic solutions,  $\alpha = 0.736$ ; Impulsivity/Carelessness: applying rash, insufficient solutions,  $\alpha = 0.833$ ; and Avoidance: avoiding problems rather than applying solutions,  $\alpha = 0.774$ ). Each item is endorsed on a 5-point scale with response options ranging from 0 (Not at All True of Me) to 4 (Extremely True of Me). The measure also yields a total problem-solving score, with higher scores indicating more effective problem solving.

Results indicated that caregivers experienced significant increases in their positive problem-solving orientation after Parent Forum I ( $M(SD)_{pre} = 12.25(4.04)$  vs.  $M(SD)_{post} = 13.96(3.47)$ ;  $t(39) = -3.12$ ,  $p = 0.003$ ). However, they also experienced a significant increase in impulsivity/carelessness problem-solving ( $M(SD)_{pre} = 4.33(3.83)$  vs.  $M(SD)_{post} = 5.28(4.34)$ ;  $t(39) = -2.14$ ,  $p = 0.039$ ). We discussed this latter finding with our *Curriculum Committee*, who suggested this could have been driven by an increase in anxiety at the end of the weekend, possibly as a result of all the information received.

We also administered a satisfaction questionnaire at the conclusion of Parent Forum I. As seen in Table 3, scores demonstrated caregivers experienced relatively high satisfaction, and 100% of participants said they would recommend Parent Forum I to someone else.

We also elicited caregiver impressions at the end of the Parent Forum I weekends as part of final wrap-up sessions. These sessions were facilitated by the Study Coordinator and Principal Investigator (the first and second authors, respectively). Caregivers made several suggestions, including having more topics addressing their children's needs. When we suggested to caregivers that we had intentionally created a program that would focus on *their* health, they countered by saying that the resolution of their children's health issues (e.g. bowel/bladder management) would facilitate their own well-being. In reflecting further on this feedback, it made sense to our team that during the limited time they had with other caregivers and with professionals with pediatric SCI expertise, caregivers wanted to profit from this network and gain more information about how best to support their children. Throughout the weekend, many caregivers also expressed concern

**Table 3** Caregiver Satisfaction with Parent Forum Sessions.<sup>1,2</sup>

Satisfaction question	Parent Forum I (n = 41)	Parent Forum II (n = 26)
<i>Response Scale:</i> 1 = No value, 2 = Limited value, 3 = Average value, 4 = Much Value, 5 = Extreme value		
	% "Much" or "Extreme" value	
How valuable were the large group educational sessions?	85.0 (n = 40)	
... on Bowel and bladder		92.3 (n = 26)
... on Sexuality and social relationships		76.9 (n = 26)
... on Transition		73.1 (n = 26)
... Discussion with caregivers of young adults		100.0 (n = 26)
How valuable were the small group activities with other parents?	97.5 (n = 40)	
... Parenting sessions (i.e. partnered vs. single parenting)		73.1 (n = 26)
How valuable were opportunities to network with program/ hospital staff?	87.5 (n = 40)	92.0 (n = 25)
How valuable were opportunities to network with other parents?	92.5 (n = 40)	88.5 (n = 26)
How valuable was dinner on Friday night		75.0 (n = 24)
<i>Response Scale:</i> 1 = Strongly disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly disagree		
	% "Agree" or "Strongly Agree"	
Did you learn things from the Parent Forum that will help you care for your child with SCI?	97.5 (n = 40)	100.0 (n = 26)
Did you feel emotionally supported during the Parent Forum?	92.5 (n = 40)	100.0 (n = 26)
Did you meet at least one other parent who you would like to keep in touch with after the Parent Forum?	97.5 (n = 40)	92.3 (n = 26)
Were you able to reconnect with at least one other parent you met during Parent Forum I?		100.0 (n = 26)
Were your individual needs considered and taken into account during the Parent Forum?	87.5 (n = 40)	92.3 (n = 26)
Would you recommend the Parent Forum to someone else?	100.0 (n = 40)	100.0 (n = 26)

<sup>1</sup>Boxes that are shaded gray indicate the question was not asked at that time point.

<sup>2</sup>Parent Forum I included 41 caregiver participants, but one caregiver chose not to complete the satisfaction survey, which explains the "n" of 40 for all the Parent Forum I responses.

regarding their children's future and adult life, suggesting that information on transitioning to adulthood would be helpful.

Logistically, parents asserted that the structure of the weekend was somewhat stressful, due to back-to-back travel days, long session times and limited free-time. They requested shorter lectures and more opportunity to speak with the professionals/speakers and discuss issues as a group. One caregiver suggested offering sessions that might be more specific to caregivers' lives, proposing a session specific to issues faced by married caregivers. Parents also suggested wanting more informal, unstructured time to talk with each other one-on-one.

### Cycle two

#### Re-conceptualization, re-development and re-implementation of the Parent Forum

After Parent Forum I, we took the findings and feedback presented above and refined our plan for Parent Forum II, which occurred August 2015 and involved the same caregivers. We adapted the structure and content for Parent Forum II to better address the needs caregivers had articulated, by: 1) changing the content to a) make sessions more discussion-based and b) include child-

focused topics; 2) streamlining travel arrangements; and 3) facilitating more organic interaction between caregivers by providing more unstructured time.

Specific to content changes, the core research team drafted a revised agenda in response to Parent Forum I caregiver feedback, and made sure to include requested child-focused topics. We then re-convened our two original groups, the *Curriculum Committee* and *Advisory Board* to further refine plans for Parent Forum II. In particular, we collaborated with small teams of *Curriculum Committee* members who strategically prepared 15-minute presentations, as opposed to the 35–40 min presentations offered during Parent Forum I. This would provide more time for questions and discussion and avoid information-overload. We further recruited caregivers of young adults who sustained pediatric SCI to participate in particular sessions. These caregiver speakers' personal contributions were a tremendous complement to our professional facilitators. We also re-convened our project *Advisory Board* of professionals and caregivers. While the professionals offered extensive suggestions related to data analyses, the group as a whole offered suggestions regarding the re-development of the Parent Forum weekend, and future directions for intervention.



We also took steps to streamline travel arrangements to reduce time constraints. We scheduled all program activities for a Saturday, allowing caregivers to arrive the day before and leave the day after the Parent Forum. This permitted caregivers more travel flexibility and unstructured leisure time. An added benefit included less variability in travel arrangements, necessitating less problem solving by project staff than in the previous year.

Finally, in addition to modifying content for Parent Forum II, we also took steps to facilitate more interaction between caregivers. In addition to structuring presentations to allow for more discussion, we held Parent Forum II on one weekend only, therefore bringing all caregivers together. We also scheduled more unstructured time for caregivers to network between presentations and throughout the weekend, outside the structured program. For example, we hosted a dinner at the hotel on Friday night, before the program began, where caregivers could get re-acquainted, and also provided them vouchers to have breakfast at the hotel on Sunday after the program had ended.

Taken together, Parent Forum II reflected the main changes we had intended in terms of structure and content (see Table 4 for the agenda). Parent Forum II topics included more child-focused issues, including sessions on bowel/bladder, sexuality and social relationships, and the transition to adulthood, and also sessions on parenting in which caregivers were able to choose between sessions on co-parenting or single parenting. Finally, the program concluded with a lengthy open-forum session with four caregivers of young

adults who sustained pediatric SCI. Sessions were 60 min in length, with 15 min dedicated to lecture and the other 45 min to questions/discussion. Sessions were again facilitated by members of the *Curriculum Committee* and/or the core research team using PowerPoint presentations.

### Evaluation of Parent Forum II

We used two methods to evaluate Parent Forum II. First, we again administered a satisfaction questionnaire at the conclusion of the weekend. As demonstrated in Table 3, we asked more session-specific questions in order to assess caregivers' satisfaction with the changes we had introduced. While there were some minor differences, overall caregiver satisfaction did not change much from Parent Forum I to Parent Forum II, and caregivers once again demonstrated relatively high satisfaction with the weekend.

Second, as Parent Forum II occurred at the end of our 12-month intervention, we hired an independent consulting group, led by the third author, to conduct focus groups with Parent Forum II participants. The focus group facilitators elicited feedback on both Parent Forum I and Parent Forum II; however, as groups were convened during Parent Forum II, this was the more salient reference point for most caregivers. Participants were broken into four groups, and analysis of focus group data was iterative and involved multiple analysts (focus group moderators and assistants). Themes that emerged relative to focus group questions were initially documented on flip charts and reviewed during focus groups with participants. After the focus

**Table 4** Parent Forum II Agenda.

DAY 1: 8:45am-6:30pm		Staff
8:45–9:30am	Breakfast:	
9:15–9:30am	Intro: Purpose Overview of the Forum Logistics for the weekend	Project Investigator (PI) Study Coordinator
9:30–10:30am	Bowel/Bladder Issues: large group session	SCI Nurse Coordinator + SCI Nurse Practitioner
10:30–10:50am	Break	
10:50–11:50am	Parenting: small group sessions (Caregivers choose Co-parenting or Sole Parenting)	Clinical Psychologists + Caregivers of former patients with SCI
11:50am–12pm	Break	
12–1:10pm	Lunch Sexual and Social Relationships	Pediatrician + Clinical Psychologist
1:10–1:30pm	Break	
1:30–2:30pm	Focus Groups	Independent Consultants
2:30–2:45pm	Break	
2:45–3:15pm	Transition large group session	PI + Study Coordinator
3:15–4:30pm	Discussion panel with caregivers of former patients/young adults with SCI	Caregivers of former patients with SCI (moderated by Study Coordinator)
5:00–5:45pm	Wrap up/questions/surveys	PI + Study Coordinator
5:30–6:15pm	Dinner	



groups, all moderators and assistants debriefed and shared thematic highlights with each other. Subsequently, moderators and assistants coded the verbatim transcript from their focus group using Krueger's Long Table Approach<sup>46</sup> and EXCEL to summarize and organize themes caregivers shared in response to the areas of inquiry explored during the focus groups. Four tables were created, one for each focus group. One of the areas in the tables was used to capture experiences with the Parent Forums and was divided into three categories: positive experiences, negative experiences, and recommendations for future such forums. Also, coders were encouraged to provide illustrative quotes/interactions from the group. One moderator was then charged with drafting a summary of themes across the groups/tables and reviewed this summary with the lead consultant (third author on the current manuscript).

Caregiver responses during the focus groups regarding the forums clustered into three major themes (see Table 5 for representative caregiver quotes):

1. Appreciation for the **quality of the information and resources shared**. Further, while caregivers appreciated both Forums, the majority expressed a preference for Parent Forum II due to a more manageable amount of content.
2. Appreciation for the ability to have time to **connect with and learn from other caregivers**. Caregivers reported the Forums provided highly valuable opportunities to connect with a community of experts and other caregivers to support each other and feel valued.
3. Recognition of the value of having an **opportunity to step out of their normal life and care routines**.

Finally, caregivers made some recommendations for future Parent Forums. They expressed a desire to have forums include learning and recreational activities for the entire family, especially their children with SCI. Caregivers also talked about the need for respite for the family; many mentioned the idea of a retreat. Further, caregivers expressed interest in more information about alternative care and treatment options or procedures (e.g. various bowel/bladder procedures, strategies to gain additional emotional support, etc.) as well as learning to effectively advocate with insurance companies and schools. Regarding logistics, participants differed in their views on Forum length. This seemed to depend on the distance they traveled to attend the Forums, with those living closer generally preferring the one-day program duration, and others living further preferring the weekend-long format. Finally, caregivers also expressed interest in personal follow-up from the hosting hospital after the Forum

ended to give updates, check-up on caregivers, and invite questions/reflections from the event (see Table 5 for representative quotes).

## Conclusion

The purpose of this manuscript was to document the process of development, evaluation, and revision of an in-person supportive intervention for caregivers of youth with SCI. While the final evaluation findings will be reported elsewhere,<sup>21</sup> it is important to share this iterative process as one model of participatory intervention development. As described, several groups of stakeholders were involved in the development of this intervention, including clinicians and researchers who work with youth with SCI, caregivers of youth and young adults with SCI, and participants themselves. Caregivers not only reported high levels of satisfaction with the overall intervention, but made several recommendations for future intervention, including efforts to support the entire family. Through collaboration and this process of development, evaluation, and revision, we were able to actualize a program specifically designed to meet the unique needs of caregivers of youth with SCI. As healthcare organizations, these types of supportive programs and action research should become routine in order to truly provide family-centered care.

## Limitations

This process highlighted several challenges of the action research framework that are important to address. While multiple cycles of intervention conceptualization, development and implementation can produce a comprehensive and effective intervention model, this process is time-consuming and resource-intensive. As described in this paper, this particular intervention took two years to develop and revise. Furthermore, the process of developing a comprehensive intervention program to address caregiver needs required expertise across multiple disciplines, including pediatric rehabilitation medicine, therapy, psychology, clinical counseling and quantitative and qualitative research methodology. Execution of this framework also involved support from funders, travel agents, and evaluation consultants, in addition to multiple site stakeholders, including the administration, support staff, clinical and research teams, and of course patient families. While we feel that the time and resources that went into this project were critical to caregivers receiving the support they needed, we realize that such time and resources are not always available. It is our hope that more published accounts such as this one can help other teams reduce the time involved with project

**Table 5 Representative caregiver quotes from focus groups.**

Representative Caregiver Quotes	
Resulting Themes	
Appreciation for quality of information and resources shared at the Forum -Articulated preference for second Forum format, although recognized the need for the first Forum in order to arrive at the second	<ul style="list-style-type: none"> <li>• "You don't know what you don't know. So it's good to find out stuff that you would never have thought of [at the forums]."</li> <li>• "The doctor [that presents] is always straightforward. I like that. And if you don't understand what they are talking about, they'll tell you in terms you can understand."</li> <li>• "They've given us really good information this year. This bowel and bladder thing, you need to know that. As much as I hate to think about it, yes, I need to know about the sex stuff."</li> <li>• "Last year's [forum] actually prompted this year's [forum presentation], because they reacted to our questions from last year. That's why we had this bladder and bowel [presentation] this year."</li> </ul>
Appreciation of time to connect with other caregivers	<ul style="list-style-type: none"> <li>• "I have found that [staying in touch with other caregivers I met at a forum] made a huge difference. I have a few people. I thank goodness this program was done, because I didn't – where I live, I don't know anybody with a kid in a wheelchair, nobody."</li> <li>• "I didn't know we had any programs in Texas until today. Another mother that's here from Texas told me about four different things that I have not ever heard of. And they're not even an hour from me. It's just being able to find those things."</li> <li>• "It's been something that, honestly, I looked forward because, for me, it's a relief to be around people who get what I'm going through."</li> <li>• "I found myself looking forward to this all year, and I don't really look forward to anything."</li> <li>• "I think the parent forums are very supportive. Somebody's thinking of us. That's what it's about. We feel valued."</li> <li>• "I find hearing other people's stories and things that their kids have accomplished and learned how to do, and going home and sharing them with the rest of my family are huge, huge."</li> </ul>
Recognition of the value in changing the routine	<ul style="list-style-type: none"> <li>• "I think getting together with other providers, plus getting – I know this sounds horrible, but getting just a break from our child, just for a couple days."</li> <li>• "I guess I'm enjoying the break from cathing and suppositories and showers, because I'm always – I cath five times a day, because she can't cath herself. So I'm enjoying that break."</li> <li>• "[When I come to the forum, I'm reminded] Because you forget to take care of yourself. You're so busy taking care of your child; you forget what you need. You don't need anything. We forget that we also need to [care for] ourselves or to read a book or just go and get your hair done."</li> <li>• "This is nice because it's not that you're by yourself. You're getting a little bit of pampering and a little bit of time for you and you're with other people. I probably laughed the most last night that I have laughed in a long time. It felt good."</li> <li>• "I love being here. This is gonna sound selfish, but I love the hotel. I love the attention to detail. They really organized this good. Yeah, they had a wonderful dinner last night. It was top of the line. They treat us kind of like you feel like you want to be treated, but you just get jilted because you're a mother or father of a special needs child, and you just get whatever's left sometimes."</li> <li>• "When I get home [from attending a forum] I feel almost regenerated. It's like, 'Okay, I can do this again.'"</li> </ul>
Recommendations for Future Parent Forums	<ul style="list-style-type: none"> <li>• "Give them [children with SCI] a separate forum, and give them something to talk about. Give them some resources, some doctors to give them some presentations, like something given to us. That would be much more helpful. (Female caregiver) Absolutely (Male caregiver) ... A couple of the kids, they are the same, similar age, so they have similar concerns. They want to learn about the sexual things, emotional development things, how to transition to adulthood, how to be more independent. So the kids, they can meet and they can share their emotions ... maybe they don't want to talk about this with us. Give them some support from the professionals ..." (Female caregiver).</li> <li>• "It would be awesome to all come together with our kids and just go do different activities."</li> <li>• "It would be great ... to have both parents present, both primary caregivers present, so that we can continue to try to be on the same page, because I know that that's sometimes a struggle for me and my husband. We're not at the same level when it comes to my son and his needs and his care. So being able to somehow facilitate both, being able to benefit from the forum."</li> </ul>

design by building on lessons learned from past projects and adapting existing intervention models for their own settings and populations.

### Strengths

This process also underscored many strengths of developing interventions utilizing an action research framework. First, involving multiple stakeholders resulted in a broader investment into the quality of intervention development. This involvement allowed a variety of individuals and teams to contribute valuable knowledge and expertise, likely resulting in greater participant satisfaction with the program. Second, involving multiple stakeholders likely helped to bring caregiver health to the forefront for the rehabilitation professionals who were involved, serving as continuing professional education regarding the ongoing needs of caregivers. Third, throughout this process, this program cultivated new connections between caregivers and this pediatric hospital, resulting in caregivers feeling supported and valued, as mentioned in several caregiver comments during focus groups. Finally, this multi-disciplinary collaboration helped clarify the role of research in this pediatric specialty hospital, and became a manifestation of the partnerships that research and clinical care can share in a clinical healthcare setting.

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